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House of Representatives

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May 2, 2001

The Honorable J. Dennis Hastert
Speaker of the House
U.S. House of Representatives
Washington, D.C. 20515

The Honorable C.W. Bill Young
Chairman, Committee on Appropriations
U.S. House of Representatives
Washington, D.C. 20515

The Honorable Ralph Regula
Chairman, Subcommittee on Labor,
Health and Human Services, and Education
Washington, D.C. 20515

Dear Speaker Hastert, Chairman Young, and Chairman Regula:

The Government Reform Committee has an ongoing oversight investigation looking at the dramatic rise in autism rates. Autism and Autism Spectrum Disorder are devastating. Autism is not simply a learning disability or developmental delay. Autism is a medical condition – a neuro-biological disorder and is characterized by patterns of delay and deviance in the development of social, communicative, and cognitive skills. There appears to be two patterns in autism – classical autism that is recognized from birth, and acquired or late-onset autism, which appears late in the second year of life and may in part be related to environmental factors such as mercury, food allergies, and vaccine injury. About eighty percent of children with acquired autism also suffer chronic bowel conditions.

Autism was once considered a rare disease affecting only 1 in 10,000 children. It is now reaching epidemic levels. Current conservative estimates place the rate at 1 in 500. However, rates are dramatically higher in some areas. For instance in Brink Township, New Jersey, the rates are 1 in 150 children. In the state of Indiana, the rate is 1 in 400

children. In Oregon it is estimated that 1 in 200 children are affected with autism. In the state of California, every three hours a new child is diagnosed with autism. While autism shows no racial or socio-economic preference, boys are four times more likely to be affected with autism than girls.

We are both proud members of the House Autism Caucus and are pleased that the Caucus is supporting an increase in funding of $20 million in 2002 for NIH's autism research budget. This is an important first step in significantly increasing the spending per affected child (400,000) from the current $140 per child NIH expenditure, and is the first installment on a three year effort to double NIH autism research. For comparison purposes, the federal government spends between $7,000 and $3,100 on research and prevention per person (between 400,000 to 900,000) infected with AIDS/HIV. Neither of us want to discount the importance of AIDS research; however, this funding disparity needs to be addressed in light of the seriousness of this emerging epidemic. We both endorse an even larger increase in autism research funding in order to move it to a position where it has the strategic priority that it deserves. The health and well being of our youth and future generations depend on it.

We are asking for your leadership in assuring the inclusion of report language further directing the NIH and CDC in this area, consistent with last year's language and the research recommendations of the Institute of Medicine review committee. Proposed language is enclosed as Exhibit One.

We appreciate your consideration of this request. The problem of the increased rates of Autism in America is going to grow dramatically. The State of California in the first three months of this year added 700 Autistic children to its rolls. Because of the severity of this disorder, it is estimated that it will cost about $2 million to care for each of these children over their lifetime. Thus, in California alone, in just the last 3 months, our nation has incurred a liability of over $1.2 billion. This level of liability is being added every three months and is growing. We have no reason to suspect that California rates are unique. This dramatic rise in autism rates is a national epidemic.

We would appreciate the opportunity to discuss this with each of you personally. Also, Stuart Burns (53671) and Beth Clay (55074) of our staffs are available to discuss this with your staff further.

Sincerely,

Dan Burton
Chairman

Dave Weldon, M.D.
Member of Congress

Exhibit One

Proposed Appropriations Report Language on Autism

Autism -- *The Committee is pleased with the expansion that has occurred in autism research and with the activities of the NIH Autism Coordinating Committee. The Committee remains concerned about reports of a possible association between the measles component of the MMR vaccine and a subset of autism termed autistic enterocolitis. The Committee continues its interest in this issue and urges the NIH Coordinating Committee to continue its commitment to give serious attention to these reports. We are pleased that the Autism Coordinating Committee has begun this research. We encourage the committee to continue this research and to specifically attempt to replicate the molecular evidence of persistent measles virus infection in children with autistic entercolitis. This research should be pursued in a way that does not cause undue harm to the Nation's efforts to protect children against vaccine-preventable diseases.*

The committee also directs the NIH to pursue, in coordination with the CDC where appropriate, the recommended research initiatives outlined in the Institute of Medicine's Immunization Review Committee report issued April 23, 2001. That report calls for the following research:

- *Use accepted case definitions and assessment protocols for Autism Spectrum Disorder (ASD) to enhance the precision and comparability of results from surveillance, epidemiological studies, and biologic investigations.*

- *Explore whether exposure to MMR vaccine is a risk factor for ASD in a small number of children.*

- *Develop targeted investigation of whether or not measles vaccine-strain virus is present in the intestines of some children with ASD. This research should involve using the most precise laboratory instruments available.*

- *Encourage all who submit reports to the Vaccine Adverse Event Reporting System to provide as much detail and as much documentation as possible when any diagnosis of ASD is thought to be related to MMR vaccine.*

- *Study the possible effects of different immunization exposures-for example, studying children whose families have chosen to have them not receive the MMR vaccine.*

- *Conduct further clinical and epidemiologic studies of sufficient rigor to identify risk factors and biological markers of ASD in order to better understand genetic or environmental causes.*

The Committee also notes that the IOM Immunization Review Committee will be issuing a report on mercury exposures in childhood vaccines. The Committee urges the NIH and CDC to pursue any research recommendations the IOM panel may issue in regard to this research.